EDITORIAL

Why the Consensus for Consensus?

The Lawson Wilkins Pediatric Endocrine Society (LWPES) meetings held in May 2008 in Honolulu, Hawaii, began with three wonderful keynote addresses that were presentations of contemporary science[1-3]. These addresses were followed by polished and witty presentations highlighting recent 'Consensus Conferences' that were joint LWPES and the European Society for Paediatric Endocrinology (ESPE) efforts[4-6]. The latter presentations were summations of the primary literature, with predictable take-home messages. Considering the contrasting presentations one can wonder where the push for 'consensus' is coming from, and what the continued evolution of the consensus conference should encompass.

The consensus statement in pediatric endocrinology is relatively new, with the first consensus statement published in 2002 about congenital adrenal hyperplasia (CAH)[7]. The conference report contained a synopsis of contemporary views of the field. Yet, although the report contained specific recommendations related to treatment, other specific nuts-and-bolts issues, such as desired hormone levels during therapy, were not addressed[7]. The recommendations related to genital restorative surgery have also been met with disagreement by members of LWPES, who thus claim the recommendations are not a 'consensus'.

A LWPES/ESPE consensus conference on diabetic ketoacidosis (DKA) brought together a wide range of expertise (pediatric endocrinology, nephrology, emergency medicine, intensive care) with the results published in 2004[8,9]. This document formed the basis of subsequent International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines[10] and American Diabetes Association guidelines[11].

The consensus statement on management of intersex disorders resulted in a major 'rewrite' of the field, showing that consensus conferences can be transformative[12-14]. A new classification of disorders of sexual differentiation was proposed, replacing the outdated terminology. However, several important issues were not tackled head-on, such as when to perform genital restorative surgery for virilized girls. Rather, compromise, not consensus, language was proffered. "Adverse outcomes have led to recommendations to delay unnecessary genital surgery to an age of patient informed consent, although relative risks and benefits are unknown."[12].

Whereas the intersex conference was transformative, the recent report on idiopathic short stature (ISS) therapy was primarily a summary of published reports of growth hormone therapy trials in short children[4]. The amount of new data presented was modest, and no changes to the current US Federal Drug Administration criteria for growth hormone use in this condition were suggested.

The report addressing the use of gonadotropin-releasing hormone (GnRH) analogs in children reviewed 300 published reports, and had a striking pocket of disagreement in the 'consensus' report[5]. Most surprising was the continued use of the 1969-based definition of precocious puberty that resulted from the evaluation of 192 children in the UK[15]. More contemporary data from 17,000 children, showing puberty to start earlier than decades ago, were eschewed. Although an LWPES-sponsored publication in 1999 advocated a rewrite of the definition, consensus could not be reached on using the new definition for precocious puberty[16]. It was very disappointing that the vast majority of recommendations presented were based on data that were not viewed to be strong and given an 'IIIC' rating. Yet, even when disclaimers are provided, consensus recommendations can give a false sense of credibility.

The presentation about the treatment of small for gestational age (SGA) children with growth hormone was a distillation of published reports[6]. The presentation also suggested beneficial effects

of growth hormone on mental health and suicide risk, based on very limited data, received with restive mumblings by the audience. As with the other reports, there was a predictable conclusion for the need for more research in the area.

It was mentioned that representatives of pharmaceutical companies were present at the consensus conferences and were described as observers, rather than active participants. Nonetheless, it can be argued that a silent presence is a visible presence. The fact that the consensus statements each involved treatments from which a number of companies reap real profits, make their presence at such meetings and their sponsorship of some consensus conferences a clear and present conflict of interest. For the sake of transparency, all corporate funding sources and the percentage of total costs paid by corporate sponsors should be plainly revealed in each publication.

It will be argued that the conflicts have been 'managed'. The bigger question is why we as a society of academicians allow corporations with strong financial interests to be present and provide financial support, either full or partial, for *our* 'consensus' reports that steer *our* treatment practices? If we cannot afford to host such conferences otherwise, perhaps that is a reflection of our priorities.

As commented previously in these pages, reviews seem to trump the primary literature in many circles. Before the presentation of consensus reports at national meetings, audience observers drew their own conclusions from the presented primary data. Although primary data were presented at the recent LWPES meetings, the quantity was limited. Of the three-day oral program, platform talks of primary research made up less than 20% of the presentations. The bulk of the primary data was in poster presentation form.

The argument in favor of the consensus report is that it is important to have such distillations of areas in which there may be consensus in therapy, or a major change in an area or nomenclature is needed. Yet, the chapters of most contemporary pediatric endocrine textbooks and review articles written by those who performed the primary studies contain similar information. Similarly, when consensus conferences are organized, the participants should be those who actually performed the primary research on the subject. This way the possible perception that consensus conferences are for the 'in crowd', their disciples and co-workers can be skirted.

We need to consider that a push for consensus can have negative effects on our field, as there is no consensus in how we think. To look for consensus in care can stifle the innovative practitioner, who may do things differently than most others, but better. We are all aware of non-consensus, non-conventional approaches from which novel therapeutic approaches have sprung, such as the application of GnRH analogs in the treatment of precocious puberty[17], and of the use of growth hormone in children born SGA[18] or with idiopathic short stature[19].

Rather then looking for consensus, we may be better served looking for the conflicts in what we do, and put these discrepant approaches in our field up for debate, as the LWPES Program Committee has been doing to great effect. We will also need to take heed of the words of a politician who said "as we know, there are known knowns. There are things we know we know. We also know there are known unknowns. That is to say, we know there are some things we do not know. But, there are also unknown unknowns, the ones we do not know we do not know."[20]. All consensus reports will have the hole of the unknown.

It is also fair to ask whether the LWPES membership is getting due return from the $100,000 or so cost per conference. State-of-the-art reviews, such as those published by the active and effective LWPES Drug and Therapeutics Committee, are written at no or little expense to the Society and are published in open access journals. These reports are thorough and scholarly, and do not aim for consensus.

LWPES has new efforts under way to start a new clinical pediatric endocrinology research network (Study Network of Pediatric Endocrinology [SNoPE]) and has allocated $20,000 to that cause. LWPES also provides important grant awards for fellows and junior faculty. Out of these efforts, true primary data will emerge that should expand our field and lead to new treatment practices and understandings of the conditions we deal with.

Rather than investing in consensus conferences that provide incremental new information and often highly qualified recommendations, we need to consider if we will get a better return on the investment of precious society funds by investing in fellows and research.

At LWPES meetings, not too long ago, much primary data was presented, and we could individually interpret how we should apply these data in our own way. Considering that the mean age of LWPES members is greater than 50 years, we certainly have a wealth of expertise to do so individually. Thus, in the spirit of 'consensus', it is hoped that there will not be 'consensus' for these comments, to which I say "yeah!". And let's begin the open debate.

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